



STATE OF WASHINGTON  
WASHINGTON STATE BOARD OF HEALTH  
1102 SE Quince Street • PO Box 47990  
Olympia, Washington 98504-7990

February 27, 2003

The Honorable Val Stevens, Chair  
Senate Children and Family Services Committee  
105 Irving R. Newhouse Building  
Post Office Box 40439  
Olympia, Washington 98504-0414

Dear Senator Stevens:

I am writing as chair of the Washington State Board of Health and the Genetics Task Force (GTF) to share the GTF's research and recommendations that support Senate Bill 5929. The legislation would require an employer or an insurer to obtain the informed consent of a person whose genetic information they collect, use, store or disclose.

The Board convened the GTF as required by the legislature last year. The broadly based group of 22 state and national experts in genetics, civil rights, research, medical ethics, regulatory matters, biotechnology, business, insurance and more transmitted their final report to the legislature just recently. The report included specific findings, conclusions and recommendations on the subject of SB 5929. I have included a copy of the final report for your information. SB 5929 appears to respond directly to Recommendation 2.3 of the report and follows from the information presented on pages 18 through 20 and conclusions presented on pages 24 and 25.

After researching the very complex patchwork of state and federal rules and laws governing civil rights and privacy protection in relation to genetic information, and after considering this information and public testimony in five day long, public meetings, the GTF's recommendations included the following:

*"Under some circumstances insurers and employers may request or obtain specific health care information about an individual. The GTF concluded that in these circumstances, the individual providing the information may not be informed of the reasons for collecting, testing, storing, or further disclosing such information. Uniformed collection, use, or disclosure of personal health information is a violation of the individual's right to privacy. ...*

*"Where current law permits the collection or use of genetic information by employers or insurers, state law should require informed consent from the individual for collection, storage, disclosure, and any use of such information. Uses of such information should be restricted to*

*those purposes for which it is collected or purposes required by law. The individual providing the information shall receive the results of any tests conducted by or for the recipient of the information."*

The Board appreciates the opportunity you provided us to convene the Genetics Task Force. We hope you find its final report and this information useful in your deliberations.

Sincerely,

A handwritten signature in black ink, appearing to read "Linda Lake", written in a cursive style.

Linda Lake  
Chair, Washington State Board of Health

Enclosure

cc: Senate Children and Family Services Committee Members  
Senator Rosa Franklin  
Washington State Board of Health Members  
Don Sloma, State Board of Health  
Ree Sailors, Governor's Office of Health Policy  
Mich'l Needham, Governor's Office of Health Policy  
Patty Hayes, Department of Health